



Alabama Department of Rehabilitation Services

# CRS *PARENT CONNECTION*



FALL 2016

## ***Grassroots campaign advocates major 'change'***

by Vera Spinks, CRS parent consultant

Glynda Arnold faces a daily dilemma with her 9-year-old grandson, Brady.

Brady was born with panhypopituitarism and is legally blind, non-verbal, and unable to walk without assistance and has incontinence issues and diabetes insipidus, which leaves him unable to control his bladder.

Brady needs his diaper changed frequently, and as he's gotten older and larger, he's outgrown the baby changing tables that are frequently found in public restrooms.

"We have no other choice but to change him in the back of our vehicle or on dirty public restroom floors," Arnold said.

When she found out about a campaign in the United Kingdom called Changing Places ([www.changing-places.org](http://www.changing-places.org)) that advocates for facilities more capable of serving people with special needs, she decided to start a chapter in Alabama to advocate

for the same equipment in the United States.

Changing Spaces Alabama ([www.changingspacesalabama.com](http://www.changingspacesalabama.com)) is a grassroots campaign that advocates for adult height adjustable changing tables and a ceiling lift system in family access and public restrooms to enable people with disabilities to have a more active and fulfilling life.

The goal of the Americans with Disabilities Act is inclusion, but many people with disabilities need more equipment that those regulations call for.

"We are mothers, fathers, grandparents, family, and friends advocating for adequate, clean and safe spaces to change our loved ones with dignity," said Arnold. "There comes a moment when you realize what you're advocating for is more than accommodations. You're really advocating for someone's quality of life."



*9-year-old Brady Arnold can walk with assistance from his father, Shane. The Arnold family advocates for clean public restrooms with larger tables so they can change Brady's diaper.*

### ***Inside:***

- > Campaign gets out disability vote in 2016
- > Cool Stuff!
- > Learning to advocate

3  
4  
5

- > Family Voices
- > CRS helps with back-to-school
- > Check out what's ahead

6  
7  
8



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Parent Connection is a complimentary newsletter published by Children's Rehabilitation Service for families of children with special health care needs. The goal of this newsletter is to increase communication and share information about children with special health care needs and their families. The newsletter reflects a family-centered theme throughout and serves as a forum for family members to share information, thoughts, feelings, concerns, etc. Nothing printed or implied in this publication constitutes an endorsement by the Alabama Department of Rehabilitation Services.

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## From the Director's Chair



*This guest column is written by newly appointed  
ADRS Commissioner Jane Elizabeth Burdeshaw.*

Dear CRS families,

In June, I was honored and humbled to be named ADRS commissioner by the Alabama Board of Rehabilitation Services. As commissioner, I oversee the department's four major programs, including Children's Rehabilitation Service.



*Jane Elizabeth Burdeshaw*

During my career with ADRS, I've served as a case manager for the State of Alabama Independent Living program, a vocational rehabilitation counselor, staff development and training coordinator, and director of Human Resource Development.

I believe all of these experiences have given me a unique perspective of the department and its programs.

As a case manager and counselor, I adopted a whole-life approach to direct service and learned that helping our consumers achieve their maximum potential requires maximum effort and wholehearted dedication. While serving in an administrative position, I developed a better understanding and appreciation for the many challenges that our staff face in providing services.

Prior to coming to ADRS almost 20 years ago, I worked at the Alabama Elks Memorial Center in Montgomery, which was a community rehabilitation program with a dormitory setting. The Elks Center is now closed, but my time there has had a profound impact on my career and philosophies. Because of my experiences there, I can recognize and respect that your perspective as the parent of a child with special health care needs is unique because living with and caring for a person with a disability is different than working with a person with a disability.

In FY16, CRS served 10,010 children with special health care needs and their families. Some people would round off the number and write "just over 10,000." I choose to use the exact number because each number represents a child. Each number represents a specific and unique set of challenges, a specific and unique set of needs and wants, dreams and aspirations.

For me, your child is more than one of 10,010 children served by CRS. Your child is ONE child, an individual person who deserves our best efforts every day in every way.

If you ever have a concern, please don't hesitate to call – because I want to hear from you. You can reach me at 334-293-7200.

Sincerely,  
Jane Elizabeth Burdeshaw  
ADRS commissioner





# Anniston's Fall Festival frightfully fun for CRS families

by Ryan Godfrey

Anniston's CRS office held their annual fall festival for children with disabilities on Oct. 26. Open to families served by CRS and Early Intervention and children from area schools, approximately 150 children enjoyed the games, food and fun at the event. Activities at the festival included a cake walk, bean bag throw, hoop toss, water balloon toss and face painting.

Both Anniston CRS and VR staff assisted with the event, and contributing sponsors included Davie School Supply, Alabama Power, State Farm, Sam's Club, Publix, the Twentieth Century Club, Central High School SGA, Puckette's, 431 Tire, the United Way, Mr. and Mrs. Brackett and Mr. and Mrs. Bumgardner.



Above left, CRS District Supervisor Randy Whitt dresses as Batman. Above right, a young firefighter sits in a real fire truck. Right, a young girl dresses as a bumblebee. Lower right, the CRS audiology booth transforms into Candy Land. Lower left, a girl dresses as a princess.



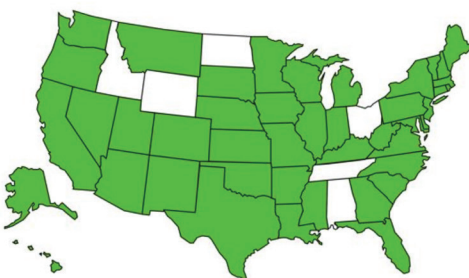
## Insurance provider to expand autism therapy coverage

UnitedHealthcare will offer a broad expansion of autism therapy coverage starting Jan. 1.

Applied Behavior Analysis (ABA) is a type of intensive behavioral treatment for autism spectrum disorder. ABA treatment is generally focused on the treatment of core deficits of autism spectrum disorder, such as maladaptive and stereotypic behaviors that are posing danger to self, others to property, and impairment in daily functioning. Types of services may include diagnostic evaluations/assessments, treatment planning, treatment and/or other procedures, medication management, individual, family and group therapy.

UnitedHealthcare is expanding the ABA therapy benefit coverage to new and renewing fully-insured small and

### 44 State Autism Benefit Mandates



Forty-four states have mandatory autism therapy benefits

large group plans in states that do not mandate ABA coverage for autism. UnitedHealthcare also recommends that self-funded plans that currently exclude ABA consider the removal of that exclusion.

Alabama is one of only six states

that is not currently providing autism families with vital services such as ABA therapy that could lead to significant improvements over time.

The insurance company reported that this change is in reaction to a growing demand for coverage of autism therapies.

The Autism society of Alabama is encouraged by UnitedHealthcare's decision to cover this autism therapy, and they applaud their efforts to expand their coverage of ABA in the state.

"It is our hope that other insurance providers will follow UnitedHealthcare's lead in providing needed therapy for children and adults living with Autism Spectrum Disorder in Alabama," said Mike Wasmer, director of state government affairs at Autism Speaks.

# Cool Stuff: brushes, boots, and bottoms

by Melissa Watson, CRS parent consultant

As parents of children with special needs, we know the value of neat things that solve sometimes tricky situations.

Take the **Surround Brush (\$8)** for example. This unique toothbrush has three sets of bristles to completely surround the tooth to clean the front, back, and biting surfaces of the tooth all at the same time.

The specially designed head ensures that more of the tooth surface can be cleaned in the time that a caregiver has. This is especially true when cooperation is limited.

The bristles of the brush are soft



*The Surround Brush has three sets of bristles to cover the entire tooth*

and rounded at the end, and the heart-shaped compact brush head helps make brushing safe and more comfortable. The grip of the toothbrush is easy to hold, and the head and neck have been designed to protect those who have a tendency to bite down on the brush.

[www.specializedcare.com/shop/pc/Surround-Toothbrushes-c37.htm](http://www.specializedcare.com/shop/pc/Surround-Toothbrushes-c37.htm)

Made in the USA, Butler has reinvented the old school overboot to deliver a bold, innovative, and iconic product to make puddle jumping fun again. The **Butler Overboot (\$50)** is practical and protective outerwear for



*The Butler Overboot fits over the child's shoe and comes in six fun colors*

kids that is available in six fun colors. The boots are designed to fit over the shoe, which makes them perfect for children who wear AFO braces. The boot is also designed to be incredibly easy to put on, helping foster a sense of independence for small children. [us.butlerboot.com](http://us.butlerboot.com)

Diapers and swimming are two things that usually don't mix, but thanks to **SnapMe Swimwear, (\$20-\$40)** diaper changing is a snap.

The swimsuits come in several fashionable patterns that kids will want to wear. Suits range in size from six

months to a child's 7/8.

SnapMe has been in business since 2009, and besides helping boys and girls when it comes to potty training and bathroom breaks, this business prides itself on also helping children with special needs. With many conditions that inhibit children from running, playing, or even walking, swimsuits designed by the company are extremely easy to put on children who have leg deformities, sensory issues, G-tubes, or other conditions where dressing can be difficult. [www.snapmeswimwear.com/snapme-for-special-needs](http://www.snapmeswimwear.com/snapme-for-special-needs)



*SnapMe Swimwear uses snaps similar to those usually seen on onesies to enable easy diaper changes*



# A parent's journey in learning to advocate

Reprinted with permission from Complex Child e-magazine

by J.O., parent

I was never good at advocating for myself. As a child, I blindly accepted, never challenged, and quietly navigated through those years without protesting treatment I did not deserve. Oddly, I became a fierce advocate for others as I grew into adulthood, and it has defined much of who I am today.

Advocacy for me began in the form of a fundraiser, then PTA president, and a member of a council. I stood before a microphone on many occasions with no fear, and spoke my mind at emotionally charged meetings to actively support and debate issues for the schools of my typical children.

After my third child was born with multiple disabilities, my advocacy took a dramatic turn, as I became a parent member of a committee for special education. I advocated for the rights of children in this system while supporting many stunned and terrified parents as a peer who knew all too well what they were feeling. I felt compelled to make sure the district treated these parents well, while I convinced them of the right choices for their precious children. Eventually, my own career path changed as I began to work as a teaching assistant for special education and taught and encouraged the children in my charge who could not speak for themselves.

As my own child with a disability grew, I found myself in constant situations of needing to question, challenge and ultimately disagree with several doctors and educators over the course of 24 years. As her support system, I will stop at nothing to make sure I am doing everything possible for her health and well-being. There are few boundaries and no such thing as giving up. Sleepless nights, days of phone calls, frustration, and tears are a way



*Advocating for our loved ones is truly one of the single most important things we can do*

of life when you are constantly standing up for what is right. Thankfully, there are also days of intense joys, and the satisfaction in knowing I have made a difference in my daughter's life, not only as her mom, but also as her voice and strength, her gentle push to try things she would otherwise never attempt.

Advocating for our loved ones is truly one of the single most important things we can do. Doctors and educators don't always have the answers and they can make mistakes. It is critical to always listen to your instincts.

My husband and I have been advocating for our daughter since the day she was born. It has not been easy. Had we listened to the advice of many and not pressed on to find the origin of

her declining health, she would not be alive today. We now have a wonderful team of experts who are our heroes, next in line to the hero who is my daughter. It took many years of research, switching specialists, and of striving for the best possible answers that brought us to where we are today. We still have far to go and it is an evolving process, but we will never stop advocating for her. As her parents, it is our responsibility to do so.

How ironic life can be. That timid little girl I once was who could never advocate for herself grew to be someone who finds it so easy and natural to do so for those in need, especially for my beautiful and inspiring daughter.

**For more information about Children's Rehabilitation Service and to stay in touch with Parent Connection, please visit us on the web at [rehab.alabama.gov/CRS](http://rehab.alabama.gov/CRS) and [www.facebook.com/CRS.ParentConnection](https://www.facebook.com/CRS.ParentConnection)**

## **Affordable Care Act: How the ACA is helping CSHCN and their families**

The Affordable Care Act (ACA) has helped both children with disabilities and their parents. Two reports from the Urban Institute (see Resources) highlight how two generations are benefiting from healthcare coverage under the ACA.

### **How Health Care Coverage is Maximized**

Research shows that when parents have coverage, their children will too. One of the Urban Institute reports stated that "... just 1.7 percent of insured parents reported that their child is uninsured ... In contrast, 25.2 percent of uninsured parents reported that their child is uninsured." Medicaid expansion data showed that uninsured parents were three times as likely as insured parents to have children who were eligible for Medicaid yet were uninsured. Making sure parents have health insurance also helps retention for children's coverage, resulting in continuity of care.

Data presented at the NJ Hospital Association showed that uninsured children and adults were diagnosed on average two to four years after their peers who had insurance coverage. This results in increased morbidity and mortality, since conditions are more severe and costly when there is a delay in diagnosis. Uninsured children and adults are less likely to access preventive services as well, which are

now provided at no cost for families under the ACA. These services include but are not limited to:

- developmental screening
- depression screening
- newborn hearing screening
- vision screening
- immunizations
- lead screening for at-risk children
- obesity screening
- special services for women

regarding pregnancy, mammograms, cancer screenings, etc.

### **What Gains Have Been Made under The ACA for Families?**

The Urban Institute reports indicate that there has been a decrease of 36% in uninsured parents since enactment of the ACA, and noted that "the share of parents with health insurance increased 6.4 percentage points and the share of children with coverage increased 1.7 percentage points – a historic high for families." Notably there were "large declines [in uninsurance rates] among low-income and Hispanic parents and a narrowing of the difference in uninsurance rates between parents and children through early 2015."

Families with insurance reported better access to care than those without insurance, which means families didn't go without care or struggle as much with medical expenses. Parents were more satisfied with the newer health plans and thought they could get care when their child needed it, which is especially important for children with special health care needs. One of the

Urban Institute reports noted that these gains have been made even though "Children were not the primary target of the ACA's coverage provisions given that they have had substantially lower uninsurance rates than parents and other adults."

The Urban Institute report cited a number of problems faced by families without insurance. "For instance, in September 2015 nearly 6 in 10 uninsured parents ... reported that their family often or sometimes ran out of food in the previous 12 months ... In addition, 45.0 percent of uninsured parents reported that they often or sometimes were unable to pay the rent, mortgage, or other housing costs; 69.3 percent had problems with unexpected bills, such as car repairs or home repairs; and 44.7 percent were unable to make the minimum payment on a credit card bill or loan."

### **Remaining Barriers**

Although there have been improvements in coverage for both children and their parents – 96.4% of children and 89.6% of parents have health insurance – there are still many children and families who are eligible for health care coverage but remain uninsured. The Urban Institute found that the most common reason for this is concern about affordability. Some families may not be aware of the subsidies available to help pay

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**For information about Family Voices, please contact the Alabama state coordinators, Susan Colburn, 334-293-7041, [susan.colburn@rehab.alabama.gov](mailto:susan.colburn@rehab.alabama.gov), or Jerry Oveson at 251-438-1609, [oveson@bellsouth.net](mailto:oveson@bellsouth.net).**



premiums. Others have incomes too high for Medicaid but not high enough (100 percent of the federal poverty level) to get those subsidies (known as the “assistance gap”). Other individuals are ineligible for premium subsidies or Medicaid due to immigration status. And parents who are ineligible due to immigration status may not realize that their children may be eligible for Medicaid or premium subsidies. Lastly, one third of uninsured families are in states that chose not to expand Medicaid. Affordability could be addressed either by Medicaid expansion and/or increased financial assistance in the Marketplace.

In sum, there have been improvements in coverage for both children with special needs and their parents. However, there are still obstacles to coverage for some families, such

as affordability, ineligibility due to immigration status, and failure of states to expand Medicaid. Additionally, there are some children and families that may not be aware that they are eligible so remain unenrolled. Overall, however, the latest data indicate that there has been increased enrollment and access to care including preventive care, which will most importantly result in better health outcomes for children with disabilities and their families.

*This tip sheet is based on an ACA blog authored by Lauren Agoratus, M.A. Lauren is the parent of a child with multiple disabilities who serves as the coordinator for Family Voices-NJ and as the southern coordinator in the New Jersey Family-to-Family Health Information Center, both housed at the Statewide Parent Advocacy Network (SPAN) at [www.spanadvocacy.org](http://www.spanadvocacy.org). More of Lauren's tips about the ACA can be found on the website of the Family Voices National Center for Family/Professional Partnerships: <http://www.fv-nctpp.org/>.*

## Resources:

### Urban Institute:

- “Time for a Checkup: Changes in Health Insurance Coverage, Health Care Access and Affordability, and Plan Satisfaction among Parents and Children between 2013 and 2015” <http://hrms.urban.org/briefs/Changes-in-Health-Insurance-Coverage-Health-Care-Access-and-Affordability-and-Plan-Satisfaction-among-Parents-and-Children-between-2013-and-2015.html>
- “QuickTake: Further Reducing Uninsurance among Parents Will Require Tackling Affordability Concerns” <http://hrms.urban.org/quicktakes/Further-Reducing-Uninsurance-among-Parents-Will-Require-Tackling-Affordability-Concerns.html>

### Georgetown University Health Policy Institute

- “Awakening the Force of Two-Generations’ (Children and their Parents) Coverage, Access and Affordability: Historic Gains Worth Celebrating in 2016” <http://ccf.georgetown.edu/all/health-coverage-access-affordability-historic-gains-celebrating-2016/>

### HealthCare.gov

- Preventive Health Services – [Healthcare.gov: <https://www.healthcare.gov/coverage/preventive-care-benefits/>](https://www.healthcare.gov/coverage/preventive-care-benefits/)

## Muscle Shoals moves to new facility

The Children’s Rehabilitation Service office and clinic in Muscle Shoals moved to a new facility in late September.

The 5,000-square-foot building is newly renovated to include a spacious clinic, state-of-the-art audiology suite, and offices for the six-member staff.

The new office, located at 714 State St., serves nearly 400 area children with special health care needs and their families.



Above, the new Muscle Shoals CRS office features covered accessible parking. CRS Below left, a vendor sets up equipment in the audiology lab. Below center, Technical Services Manager Tyler Mason prepares a grounding cable for the Muscle Shoals CRS server room. Below right, Office Coordinator Kimberly Wright and CRS Nurse Laura Akers look over the furniture delivery.





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## ***Check Out What's Ahead ...***

### **Feb. 24, 2017**

#### **16th Annual Alabama Autism Conference**

**Description:** This conference focuses on understanding the unique and varied social and emotional skills exhibited by individuals with ASD and ways to support their development and functioning. The conference is held in Tuscaloosa and sponsored by The University of Alabama.

**Information:** [www.training.ua.edu/autism](http://www.training.ua.edu/autism)

### **Feb. 26-28 2017**

#### **2017 Alabama disABILITY Conference**

**Description:** Self-advocates, family members, caregivers, educators, lawmakers, direct support staff and others are invited to attend this conference to learn more about resources, trends, and future plans for the ID/DD community. The conference will be at the Montgomery Renaissance Hotel and Spa. Registration is \$240. Families may qualify for special rates through the Alabama Council for Developmental Disabilities.

**Information:** [www.aldisabilityconference.org](http://www.aldisabilityconference.org)

### **April 20-21, 2017**

#### **Partners in Care Summit**

**Description:** Family Voices of Alabama and the Family to Family Health Information Center project will host the seventh annual Partners in Care Summit at the Montgomery Prattville Hotel & Conference Center at Capitol Hill in Prattville.

**Information:** Trish Switzer, 1-877-771-3862

***Local PAC meetings: Check your local CRS office for dates and times of meetings in your area.***